## ABSTRACT

The 2000 census, with its option for respondents to mark 1 or more race categories, is the first US census to recognize the multiethnic nature of all US populations but especially Asian Americans and Native Hawaiians/Pacific Islanders. If Asian Americans and Native Hawaiians/Pacific Islanders have for the most part been "invisible" in policy debates regarding such matters as health care and immigration, it has been largely because of a paucity of data stemming from the lack of disaggregated data on this heterogeneous group of peoples.

Studies at all levels should adhere to these disaggregated classifications. Also, in addition to oversampling procedures, there should be greater regional/local funding for studies in regions where Asian American and Native Hawaiian/ Pacific Islander populations are substantial. (Am J Public Health. 2000;90: 1731–1734)

## Toward Improved Health: Disaggregating Asian American and Native Hawaiian/ Pacific Islander Data

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Asian American and Native Hawaiian/Pacific Islander communities realize the political importance of the revised standards of Office of Management and Budget (OMB) Directive 15, which requests and classifies information on specific ethnic categories. These counts or numbers by racial category provide crucial information to groups that lobby for resources for redistricting and policy development. The perspectives and methods used for conducting studies on these ethnic groups and on the data collected, besides having far-reaching policy implications, have as a goal providing communities with information critical to serving their health needs. The revised OMB Directive 15 is making a first step toward achieving this goal. This commentary highlights the areas of "invisibility" of Asian Americans and Native Hawaiians/Pacific Islanders, thereby pointing to the need for disaggregating the racial data for public health.

## The "Invisibility" of Asian Americans and Native Hawaiians/Pacific Islanders

Asian Americans and Native Hawaiian/ Pacific Islanders have to a large degree been "invisible" in public health debates and their interests disregarded in immigration law and practices, and these factors have obscured our understanding of the sociocultural and ecopolitical factors that influence their health and quality of life. We will focus on a few areas that illustrate this invisibility: the concepts of health and health care, the diagnosis and detection of diseases, treatment and dosage levels, social histories, and, finally, immigration laws and practices.

## Concepts of Health and Health Care

There is ambiguity in the concepts of health and health care for the subgroups of the Asian American and Native Hawaiian/Pacific Islander populations. A study done by Hinton and Friend in Boston's Chinatown showed that there is no equivalent word in any of the Chinese languages for Alzheimer disease; the Chinese understand it as an imbalance in the chi (the source of life and energy). They thus have a different notion of Alzheimer disease and do not follow a Western or allopathic biomedical model of the disease and its progression. This

has several implications for data and for the model and kinds of care to be provided.

## Diagnosis and Detection of Diseases

To a large extent, the health care system fails to understand the complexity and diversity of the health risks of immigrant and ethnic populations. There are severe gaps in our knowledge of the health needs of Asian Americans and Native Hawaiians/Pacific Islanders, and of the illnesses from which they suffer, because of the lack of group- or ethnicity-specific data.<sup>2,3</sup> For example, Vietnamese women have the highest rate of cervical cancer among women of all racial and ethnic categories.<sup>4</sup> Also, standards for the detection of diseases have not been developed for the various ethnic subgroups of Asian Americans and Native Hawaiians/Pacific Islanders, which leads to inadequate health care services. Southeast Asian women, for instance, have a high incidence of cervical cancer owing to a lack of Papanicolaou test examinations. 5,6 Similarly, type 2 diabetes mellitus is prevalent among Pacific Islanders (especially Samoans and Native Hawaiians) even though it can be prevented through early detection.7

## Treatment and Dosage Levels

Data are scant for determining levels of dosage for Asian Americans and Native Hawaiians/Pacific Islanders, who have different metabolisms, diets, heights, and weights vary by subgroup.<sup>8</sup> Even in cases where the health problem has been identified, doctors do not recommend similar therapies for Asians and non-Asians. For example, Asian American women are less likely to receive hormone replacement therapy than are White women.9 Since Asian Americans and Native Hawaiians/ Pacific Islanders often use alternative medical therapies, we need to understand the role of these therapies and also look at the conjunction between these traditional practices and

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those of Western medicine. <sup>10</sup> In this regard, we also need to look at the interactions of allopathic medicines and herbal medications. <sup>11</sup>

The "invisibility" of Asian Americans and Native Hawaiians/Pacific Islanders is also seen in a lack of attention to the social, political, and economic histories of Asian Americans and in immigration laws and practices.

#### Social Histories

The social, political, and economic histories of Asian Americans and Native Hawaiians/ Pacific Islanders and the variability within these subgroups are not accounted for in assessments of their health. A case in point is the Hmong, who were "transferred" to different refugee camps in Laos, Thailand, and China before many of them settled in the Central Valley of California. Their unique experience of being refugees, of losing connections with family and kin, and of living in poverty has implications for the general health and mental health of this population. Their histories may have little in common with those of other Asian Americans and of Native Hawaiians/Pacific Islanders. 12

## Immigration Laws and Practices

The federal and state governments' immigration laws and practices have led to questions of eligibility and access to care. In California, for example, anti-immigrant sentiment and the passing of Proposition 187 have led to confusion over access to several health care programs, such as Medi-Cal, resulting in eligible immigrants not even attempting to apply for these programs.<sup>13</sup> Recently, the much-publicized issue of the role of the Census Bureau in providing information to the War Department during World War II on "concentrations of people of Japanese American ancestry in geographic units as small as city blocks" on the West Coast<sup>14</sup> has led many Asian Americans to be wary of participating in the 2000 census. All of this contributes to a lack of confidence in the US government and its institutions, which in turn leads to lower census return rates and, hence, less accurate information.

# Heterogeneity and the Need for Disaggregation

The "invisibility" of Asian Americans and Native Hawaiians/Pacific Islanders has led to assumptions of their homogeneity; they have been aggregated into 2 groups or into 1 undifferentiated group, or, worse still, they have been grouped within the "other" category. 5,15 In this regard, we have to be cognizant of the differences between racial and ethnic identity. Asian

American identity is a political identity, that was nonexistent before the individuals' immigration to the United States from countries as diverse as China and Sri Lanka. On the other hand, ethnic identity for Asian Americans and Native Hawaiians/Pacific Islanders may be based on cultural, linguistic, and/or geographic factors. In a similar vein, immigrants from the Middle East, who are from different ethnic cultures, are not provided a separate racial category in the revised OMB Directive 15 and will be categorized with other racial groups (most likely "White"), even though their social, economic, political, and cultural experiences and histories are very different. By subsuming them under some other larger racial category, however, we ignore the health and health care needs of this growing population, who are faced with a lack of culturally and linguistically appropriate services. In fact, some of the peoples from South Asia may have more in common culturally and linguistically with peoples from the Middle East than with peoples from East and Southeast Asia.

In highlighting the variations among Asian Americans and Native Hawaiians/Pacific Islanders, who are culturally diverse, exceedingly heterogeneous, and the fastest-growing group in the United States, <sup>16</sup> we focus on 3 issues: income and poverty, discrimination, and the process of adjustment.

## Income and Poverty Levels

There are extreme variations in income and rates of poverty among these subgroups, and these variations affect the health of the community.17 For example, Asian Indians and Japanese have median income levels of over \$30000, while Laotians have median income levels far below \$10000. The percentage of people with incomes below the poverty line varies from 6% for Filipinos to as high as 63% for Hmong. Moreover, in many of these communities, such as the Hmong and Cambodians, a majority of people (over 60% in both the Hmong and the Cambodian communities) are linguistically isolated, 18,19 which further marginalizes them and exacerbates their poverty.

#### Discrimination

For some Asian Americans and Native Hawaiians/Pacific Islanders, there is a long history of discrimination, including internment, limited rights with regard to buying and owning land, lack of citizenship, and having to contend with the common assumption that they are not "real" Americans or "full-fledged" US citizens. <sup>20,21</sup> These experiences have led to fears of reprisal and rejection and have been an ob-

stacle to gaining access to and using health care services.<sup>23</sup>

## Process of Adjustment

Generational factors and the process of adjustment to living in the United States also have an impact on health and mental health. There are variations in the level of adjustment between first-generation and third-generation Japanese and Chinese and between the highly educated Asian Indians, Chinese, and Koreans who work in Silicon Valley and the lessqualified, less-acculturated Hmong and Laotians in the Central Valley of California. 23-25 This heterogeneity in the process of immigration and adjustment to the United States, with its concomitant process of unlearning and learning of "new ways," has led to differences in seeking assistance for health and mental health care needs. 26-28 When data on Asian American and Native Hawaiian/Pacific Islander ethnicities are aggregated, rates of health care use may be high overall, but the rates are higher among highly acculturated Asian Americans and Native Hawaiians/Pacific Islanders and lower for others. This may lead us to ignore issues such as offering culturally relevant services through providers that are both bilingual and bicultural.<sup>29,30</sup>

## The 2000 Census

It is clear from the preceding discussion that there are valid reasons to disaggregate data for the Asian American and Native Hawaiian/Pacific Islander ethnic groups. Concerning the revised OMB Directive 15 and its resulting format in the 2000 census, we would like to comment on 2 issues, mixed racial categories and undercounting.

## Mixed Racial Category

With the "mark one or more" option in the 2000 census, for the first time in the US census there will be categories that show a combination of racial categories. For Asian Americans and Native Hawaiians/Pacific Islanders, the category that will surely be reported is the Asian and White mixed racial category. This is of interest and relevance because some studies have indicated that, of persons identifying themselves as multiracial, 30% are Asian American or Native Hawaiian/Pacific Islander. 31 Also, 43% of second-generation Asian women and 35% of second-generation Asian men marry outside the ethnic community.<sup>32</sup> We know very little about the health and mental health of this mixed racial population, however. Although there are benefits to getting an overall picture, once again, when the Asian

American subgroups are collapsed, the nuances of the Asian American ethnicities are not available to the relevant communities. The inadeguate sample sizes within the Asian American and Native Hawaiian/Pacific Islander groups may not make it economically feasible to report on their mixed ethnicities. However, Asian Americans and Native Hawaiians/Pacific Islanders are fast-growing groups, and there is need for a detailed understanding of the relations between ethnicity and the health of these populations.

## Undercounting

There is concern in the Asian American and Native Hawaiian/Pacific Islander communities about being undercounted in the census. First, although forms for the 2000 census are available in several Asian languages (Mandarin, Cantonese, Vietnamese, Korean, and Tagalog) and assistance is available in 50 other languages, there could be an undercount of people whose native language or dialect is not represented in the census forms. Second, some people will avoid being counted in the census because they fear reprisal-reasonably, if one considers the immigration laws and the general population's attitude toward immigrants, despite assurances from the Immigration and Naturalization Service (of which immigrants are always wary) that the information will not be used in that way. Third, there is the problem of misclassification. When Chinese from Vietnam categorize themselves as Chinese, which may be ethnically appropriate, we are unaware of their unique social, economic, and political histories and may not fully understand, among other things, the mental health stressors of the immigration process. Also, in discussions of the issue of ethnic classification with Punjabis in northern California, it has been found that some Punjabis do not identify themselves as Asian Indian because of the history of the Khalistan separatist movement in India.

## Challenges for Public Health Data

All of the factors discussed in the foregoing paragraphs have implications for public health and health care policy. The 3 issues that need to be considered are national disaggregation limitations, lack of a numerator, and methodology.

## National Disaggregation Limitations

When there is an inadequate sample size in national public health data, it might make "research sense" to aggregate the Asian Amer-

icans and Native Hawaiians/Pacific Islanders into 1 or 2 groups, but we forget that the aggregated data are not of much use for communities that serve specific ethnic populations. The people who most need the disaggregated data are the community service providers and policymakers.

## Lack of a Numerator

The aggregation of data results in the lack of a numerator for health/disease for the Asian American and Native Hawaiian/Pacific Islander ethnic groups. This results in an inaccurate statistic, leading to inadequate services or, in the worst case, no services at all.

## Methodology

In developing this disaggregated numerator, we need to be aware of the methodology and purpose of the studies that are conducted in the Asian American and Native Hawaiian/Pacific Islander communities. These have an impact on the validity and reliability of the data gathered. Some important questions that need to be addressed are whether the instruments used were culturally appropriate, what languages the study was conducted in, whether translations were culturally valid and cognitively pretested, and whether the study was conducted in collaboration with the community.<sup>33</sup> An issue that requires special attention is the fact that Asian and Pacific Islander languages generally are not used in most national and regional studies; given that only English-speaking Asian Americans and Native Hawaiians/Pacific Islanders are interviewed, the resultant data are skewed.

## Recommendations for Public Health Studies

Because the 2000 census includes the item of ethnicity/race category, the fast-growing Asian American and Native Hawaiian/Pacific Islander groups will now have the denominator information for many of the ethnic categories that was lacking in the earlier census. We therefore make the following recommendations for health data:

- Oversample. At the national level, Asian Americans and Native Hawaiians/Pacific Islanders should be oversampled. An alternative is to conduct the same study on different ethnic groups every year, avoiding a repeat of the same groups; this way, there would be at least some data on each of the ethnic communities to reflect the changing nature of their
- · Create greater funding for regional and local studies. For regions where substantial

numbers of Asian Americans and Native Hawaiians/Pacific Islanders reside, increased funding should be made available for regional and local studies. For example, the California Health Interview Survey (conducted by the Center for Health Care Policy at the University of California, Los Angeles) is a first-time large-scale effort to look at various ethnic communities within a state.

- Disaggregate the ethnic data. The process of arriving at the revised standards of OMB Directive 15 has once again shown us the expediency of disaggregating ethnic data. We should adopt and report ethnic breakdowns for all studies. Such disaggregated data should be reported in the body of the text (e.g., along with the sample profile) rather than in an appendix. The Asian and Pacific Islander American Health Forum has developed guidelines for reporting the unavailability of and missing data on Asian Americans and Native Hawaiians/Pacific Islanders.34
- Ask for immigration information. When doing regional and local studies, it may be necessary to obtain immigration information from Asian Americans and Native Hawaiians/Pacific Islanders. This is a delicate issue, but this information is pertinent to an understanding of the health of the population. For example, in the Current Population Survey, which provides critical information on the changing demographics of the US population, questions that address generation, year of immigration, and length of stay in the United States should be included. In this way, the mother's or father's country of citizenship would not have to be used as an identifier for ethnicity, thereby avoiding erroneously categorizing all US-born Asians as "other Asians."
- · Limit generalizations. In view of the significant variations among Asian Americans and Native Hawiians/Pacific Islanders, generalizations should be limited to the ethnic population on whom the data were gathered and not extended to the entire population.

Some of the recommendations and issues may have to be refined and may be contentious. Our goal is not to racialize or stereotype the populations. Rather, we seek to better understand and provide relevant services for health and mental health care and to work toward the goal of a healthier population with improved quality of life. To achieve these goals, the disaggregation of data on Asian Americans and Native Hawaiians/Pacific Islanders and on mixed racial categories is crucial.

## **Contributors**

Both authors contributed equally to the conception of the study, the collection and analysis of the data, and the writing of the paper.

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